

Utah Registry of Autism and Developmental Disabilities



Volume 1; Spring 2004

Welcome!

The Utah Department of Health welcomes you to the first edition of the Utah Registry of Autism and Developmental Disabilities' newsletter! We want this quarterly newsletter to be useful for you and your family. Please send your comments or suggestions to us by phone at (801) 584-8547 or via email to jeniferlloyd@utah.gov

Behavior Skills



Each edition of this newsletter will include a behavior skills section – it will talk about a behavior topic that many families have had to address. While this section cannot and does not take the place of a visit with a clinician or other behavioral specialist, we hope that you will find the suggestions useful. For this newsletter, we have some useful tips on 'Increasing Independence' from Judith Miller, Ph.D. Dr. Miller is a child psychologist who works with the University of Utah Medical Center Department of Psychiatry.

Increasing Independence

Many parents wonder when and if their children will master self-help skills, from dressing themselves to using public transportation. How do you know when a child is "ready" to learn a particular skill? Are there some things that a child with autism will never be able to do on his or her own?

Research has shown that children with autism and other developmental disabilities can and do learn self-help skills. However, sometimes it is necessary to teach each individual task, such as dressing, eating with utensils, cleaning up, and using the bathroom. Entire books have been written on how to teach self-help and independent living skills to individuals with special needs. An excellent resource is Steps to Independence, by Bruce Baker and Alan Brightman (Brookes Publishing Co.) Here are some suggestions:

✓ **Consider typical development.**

Don't try to teach complex skills that typical children of the same age would not be able to master. It will probably just frustrate you and your child. Most children with developmental disabilities struggle in many areas, so it should be possible to find a skill your child needs to work on that typically developing children of the same age are also learning or have already mastered. Some examples might include dressing, using eating utensils, washing hands, and putting toys away. All of those skills are important throughout life, and form the foundation for more complex tasks (such as choosing appropriate clothing for the weather, using appropriate manners when eating, personal hygiene, and keeping a clean room or house).

✓ **Look for signs that the child is ready to learn the skill.** For example, if your son can take off his clothes independently, he can learn how to put them

on. If your daughter can get toys out of the toy box, she can learn how to put them back. If your son can manipulate small toys, he is ready to learn how to eat with utensils. If your teenager or adult is not intellectually impaired, she probably has the capacity to learn how to use public transportation, as well as keep track of her own spending money.

✓ **Give your child enough time to try it on his own.** Yes, you'll get through the morning faster today if you pick out the outfit and put it on for your child. However, just as we get in the habit of doing things for a child, sometimes the child gets in the habit of passively having things done for her. To change that habit, pick a specific task you want your child to learn and then plan for the extra time it will take her to practice and master it. If it's dressing, it may take 10-20 minutes longer in the morning for your daughter to struggle with her own shoes. If it's learning to ride the bus it might require several months of repeated practice. But it will be worth it!

✓ **Get a fresh perspective on what your child can and can't do.** Try this: Think about a task you want your child to do independently, such as dressing. Then, think about how it usually goes. Does the child start getting dressed without a reminder? Does he pick out appropriate clothes? Does he put them on without help? Does he put pajamas and dirty clothes away without being asked? If you weren't in the room, would he be able to get dressed by himself? If not, what is it that you help with? Do you need to remind him of certain steps, help because of motor deficits, etc.? If you have to be in the room, give reminders, or clean up afterward, is he *really* doing the task, from start to finish, on his own?

✓ **Stop yourself before you rush in to help.** The next time your child needs to get dressed, stop yourself from doing every step for her, and wait long enough to see if she will begin to do it herself. See if she will reach for a shirt from the drawer, or reach for the pants herself without a prompt. If about 5 seconds pass and she hasn't moved, ask a general question to get her back on task (such as "What do you need to do?"). Give her another 5 seconds before offering the answer or helping get her started. When each small step is done (e.g., putting the shirt on), then stop yourself

before the next step (putting pants on) and before the step after that (putting socks on), etc. Wait each time to see if your child can figure out what to do next, and prompt her only when she doesn't start the next step on her own.

In working with families, the hardest part seems to be stopping and waiting long enough to see if the child will do the task himself. We become so used to doing certain things for the child it takes a conscious effort to break out of our own routine! But, by waiting to see what the child does BEFORE we prompt him and BEFORE we do it for him, we can see exactly what he needs to work on.

So: expect the child to be an active participant, stop yourself from doing the task for her, and provide prompts that get the child thinking about what she is doing rather than simply following directions. Then make it fun! Getting dressed is great because now she can play outside, eat her favorite breakfast, or watch TV!

Families' Corner

In this section of the newsletter someone whose life has been impacted by an autism spectrum disorder offers his or her perspective. If you are interested in writing an article for a future newsletter, please contact us.

Our parent contributor for this first newsletter is Catherine Parry. Catherine is a parent representative to URADD, and a co-editor for this newsletter. She resides in Provo with her husband, Joe, and their almost ten-year-old son, Will.

A couple of weeks after we learned that our then four-year-old son was likely autistic, a little bird flew hard against our living room window and fell to the ground. Usually they lay stunned, but this one frantically keeled over and over. As I hesitated what to do for it, I had the sudden thought that the bird was William, our son, and I must do for it what I would do for him. So I rushed out and gathered it tightly into my hands to stop the frantic motion. The bird stilled and closed its eyes, though I could still feel its frightened heartbeat. We sat there for many minutes while I waited for

it to die – after such a hard hit, how could it not die? – and all the while I thought, “This is Will, and this is what I must find a way to do for Will.” The bird opened its eyes and moved a tiny bit, so I loosened my grip. It made a “gawk” sound, then flew straight and purposefully to the wild rose behind the fence.

The image of the frantic, fluttering bird has been an apt one for Will, whose autism and bipolar disorder cause his days to be filled with extravagant mental and physical movement. My husband and I constantly seek ways to gather him metaphorically into our hands and still or direct his chaos. When he is at his most frantic, usually when he is around people, we tighten our grip to confine him, but find that, unlike the bird, the ten-year-old boy struggles against our hold. He now demands an independence that we fear he is not mature enough to handle. We find it hard to loosen our grip, difficult to help him discover the balance between his desires and his capacity.

In fact, we cannot always discern his capacity, what he can’t do from what he won’t do, and what he has simply become used to having us do. I found Dr. Miller’s article on independence (in this newsletter) to be a useful guide to discerning and increasing Will’s ability to act on his own. I fear that too often I, not his autism or bipolar disorder, am the limit to his independence. If I could remember the lesson of the bird, and loosen my grip whenever possible, then perhaps I will more often enjoy the relief of watching him fly, even if only a little way.



What’s New?

This section of the newsletter will include a summary of a recent research article that looks at autism spectrum disorders or other developmental disabilities. If you are interested in reading the entire article, you

can get it from your library, or contact us and we will help you get a copy.

Article Name: Specifying PDD-NOS: A Comparison of PDD-NOS, Asperger Syndrome, and Autism.

Authors: Walker DR, Thompson A, Zwaigenbaum L et al. **February 2004**

Journal reference: *J Am Acad Child Adolesc Psychiatry* 2004; 43 (2): 172-180.

This study compared children diagnosed with PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified) to children diagnosed with either autism or Asperger Syndrome (AS). The reason for the study was to look for similarities and differences both within the PDD-NOS group, and between it and the other two groups.

The researchers administered standard tests, and then compared the test results from the three groups of children. They found that two-thirds of the children with PDD-NOS had test results that were similar to each other’s. Their results were also more like those of the children with AS than those of children with autism. The main differences between the group of children with PDD-NOS and the group of children with AS were in speech, intelligence scores, and repetitive behaviors. Children with PDD-NOS tended to begin speaking later and to have lower intelligence scores than children with AS; they also had fewer repetitive behaviors than children with AS.

The researchers did not find any common pattern in the remaining one-third of the children with PDD-NOS. When compared to all of the children diagnosed with PDD-NOS, these children were often younger or had more significant developmental delays. This may have made it more difficult for the researchers to test them.

The researchers concluded that two-thirds of the children who had been diagnosed with PDD-NOS had a lot in common with each other. If further studies find similar results in other children with PDD-NOS, the researchers suggested that a new diagnosis be set up for these children separate from the diagnosis of PDD-NOS. This would allow clinicians to diagnose these children more accurately and, at the same time, give families a better picture of how they can help their child.

Upcoming Events

This section of the newsletter will include a list of upcoming events that we think you might find of interest. If you know of an upcoming event that parents and families affected by autism spectrum disorders would appreciate, please call 801-584-8547 and let us know. Also, check our website under 'Research and Training' to look for upcoming events:

<http://health.utah.gov/autism/Research.htm>

A Reminder and a Request for Help!

Please visit our website and tell others about it: <http://www.health.utah.gov/autism> We update it monthly. If you would like something on the website that you don't see there, please contact us and let us know.

Finally, URADD needs your help! We want all Utah families affected by an autism spectrum disorder to know about us. If you know other families who fit this description, please share this newsletter with them, or tell them about our website.

Become Part of the Utah Registry of Autism and Developmental Disabilities!

The Utah Registry of Autism and Developmental Disabilities is always looking for Utah residents who have an autism spectrum disorder to become part of the registry. The registration form is available online:

<http://health.utah.gov/autism/Registry.htm>

You can also request a registration form over the phone, by fax, or by mail (Please see the contact information in the next column.).

To contact us:

Mailing Address

Utah Registry of Autism and Developmental
Disabilities
Utah Department of Health
P.O. Box 144643
44 North Medical Drive
Salt Lake City, UT 84114-4643
URADD@utah.gov

Phone Numbers

Within Salt Lake City: (801) 584-8547
Outside Salt Lake City: (800) 829-8200 Ext. 1
Fax: (801) 584-8579

URADD Investigators

Dr. Judy Pinborough Zimmerman
Children with Special Health Care Needs
Utah Department of Health
44 N. Medical Drive
Salt Lake City, Utah 84114

Dr. William McMahon
University of Utah School of Medicine
Department of Psychiatry
50 N. Medical Drive
Salt Lake City, Utah 84132